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Designing Informed Consent for AI Tools - Supporting Real Choice for Global Majority Users

Our sixth and final session in the Equity & AI Learning Series tackled a topic that sits at the heart of responsible AI, but is often overlooked: informed consent. As AI-powered tools become more common across international development and humanitarian programming, organizations are collecting increasing amounts of personal and sensitive data. Yet many users still have little understanding of what happens to that data, who can access it, how it may be used, or what choices they actually have.

To explore these questions, we were joined by **Isabelle Amazon-Brown**, a digital development consultant with extensive experience designing award-winning chatbots, mobile platforms, and digital services across Africa, Asia, and Europe. Her work focuses on inclusive design, gender, safeguarding, and responsible AI, and she has supported organizations including Girl Effect, UNICEF, and SVRI to develop practical guidance on ethical chatbot and AI design.

Through live examples, prototype testing, and discussion, participants explored why current approaches to informed consent often fall short, particularly in Global Majority contexts where differences in language, literacy, digital access, legal protections, and power shape people's ability to make informed choices. The conversation challenged organizations to think beyond privacy policies and compliance requirements and instead ask a different question: **How can we design AI tools that genuinely support understanding, agency, and informed decision-making?** One message came through consistently during the session: informed consent is not simply a legal requirement. It is part of good design. Organizations that invest in making consent more understandable and meaningful are also building stronger trust, more ethical AI systems, and better experiences for the people they serve.

Why This Session Matters

AI-powered tools are rapidly becoming part of development and humanitarian programming, from chatbots and digital health platforms to research, monitoring, and service delivery. Yet one important question is often overlooked: do users actually understand what they are agreeing to when they share their data?

For many organizations, informed consent has become a legal requirement rather than a meaningful user experience. This session challenged that assumption, showing how better consent design can strengthen trust, support user agency, reduce risk, and ultimately lead to more ethical and effective AI systems. It also offered practical ideas that organizations can begin applying immediately, whether they are designing new AI tools or reviewing existing digital platforms.

Understanding Informed Consent in the Age of AI

What is informed consent?

The UK and EU General Data Protection Regulation (GDPR) defines consent as: "Any freely given, specific, informed and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her." This definition has shaped privacy legislation around the world, but it also raises an important question: What does it actually mean for consent to be freely given, specific, informed, and unambiguous when people are interacting with AI systems? Throughout the session, Isabelle challenged participants to think beyond legal compliance and consider what meaningful informed consent looks like in practice.

Meaningful informed consent should be:

- **Freely given:** People have a genuine choice. They can decide not to participate without coercion, manipulation, or losing access to essential services.

- **Specific:** Consent is requested for clearly defined purposes. Users know exactly what they are agreeing to, rather than providing blanket permission for future or undefined uses of their data.
- **Informed:** People understand what data is being collected, why it is being collected, how it will be used, who may have access to it, the potential risks, and how they can change their decision later.
- **Unambiguous:** Consent is communicated through a clear, deliberate action. It is never assumed through silence, pre-selected options, or confusing interfaces.

Taken together, these principles set a much higher standard than simply asking users to click "Accept." They require organizations to design experiences that genuinely support understanding, choice, and agency.

Why is informed consent becoming more difficult?

AI is changing the nature of informed consent. Data often moves across multiple systems, models continue to evolve after deployment, and future uses of data may not be fully known when consent is collected. Many AI systems also operate in ways that are difficult for users to understand or for organizations to fully explain. At the same time, AI is increasingly being used in contexts involving highly sensitive information, including health, education, livelihoods, migration, child protection, and gender-based violence.

The risks of poorly designed consent

One of the strongest messages from the session was that poor consent design creates real risks for both users and organizations. The consequences exist on a spectrum, ranging from minor inconvenience to systemic harm. **For users, poorly designed consent can result in:**

- Receiving unwanted communications because they did not understand how their data would be used.
- Sensitive personal information being shared, retained, or used in ways they never expected.
- Physical, legal, or emotional harm when information from AI systems is accessed or disclosed inappropriately.
- Surveillance, discrimination, or criminal prosecution in contexts where personal information relates to sensitive issues such as health, sexual and reproductive rights, migration, or sexual orientation.
- Systemic harm when data practices reinforce existing inequalities, concentrate power, or expose already marginalized communities to greater risk.

For organizations, poorly designed consent can:

- Reduce trust in digital services and discourage people from using them.
- Damage organizational reputation and public confidence.
- Create legal, ethical, and regulatory risks.
- Reduce employee confidence and trust in organizational data practices.
- Limit the quality of feedback, learning, and evidence when users participate without fully understanding how their information will be used.

The session emphasized that better consent is not simply about reducing risk. It is also about building trust, strengthening relationships with communities, and creating AI systems that people can use with greater confidence.

Why there are no easy answers

One of the strengths of the session was that it acknowledged there are no universal solutions. Designing informed consent requires organizations to balance competing priorities, and those trade-offs will look different depending on the context.

For example:

- Giving people meaningful choice while still delivering essential services. Can consent be considered "freely given" if declining means losing access to food assistance, healthcare, or education?

- Protecting children without creating new privacy risks. Requirements for parental consent can be difficult to implement in many contexts and may require collecting even more personal information, creating additional privacy and surveillance concerns.
- Respecting cultural differences while protecting individual rights. Expectations around privacy, family decision-making, and autonomy vary across cultures, raising important questions about how consent should be designed without imposing a single worldview.
- Keeping pace with rapidly evolving AI systems. AI technologies are changing faster than most laws, policies, and organizational practices. Decisions made today about consent may become embedded in AI systems for years to come.

These tensions reinforce an important point: informed consent is not something organizations can solve with a better privacy policy or a new legal template. It requires ongoing reflection, user testing, and thoughtful design that responds to the realities of the people using AI systems.

Designing Better Informed Consent: Practical Lessons for Organizations

1. Treat informed consent as a design challenge, not a legal exercise

Many organizations approach informed consent as a legal requirement that must be completed before someone can access a service. The session challenged this thinking. Consent is part of the overall user experience and should be designed with the same care as any other feature of an AI tool. The goal is not simply to obtain permission. It is to help people understand enough to make an informed decision.

What organizations can do:

- Bring consent discussions into the product design process from the beginning, not just during legal review.
- Involve designers, safeguarding specialists, MEL teams, legal advisors, and end users in developing consent approaches.
- Test consent alongside other features during usability testing.

2. Stop expecting users to read privacy policies

Research consistently shows that lengthy privacy notices are rarely read or understood. Isabelle shared behavioural research demonstrating that people experience consent fatigue, cognitive overload, and often click "Accept" simply to reach the service they want.

What organizations can do:

- Replace legal language with plain-language explanations.
- Present information in layers, starting with the most important points and allowing users to access more detail if they choose.
- Consider visuals, icons, videos, or interactive examples to explain how AI uses data.

3. Think about the entire consent journey

Consent should not happen once at registration and never be discussed again. Organizations should think about multiple opportunities to explain data use, remind users of their choices, and allow them to revisit or change their decisions as they continue using a service.

What organizations can do:

- Build opportunities to revisit consent throughout the user journey.
- Notify users when data will be collected or used in new ways.
- Make it easy to review, update, or withdraw consent at any time.

4. Measure understanding, not agreement

Collecting consent does not mean people understood it. The session challenged organizations to shift from asking "Did the user agree?" to asking "Did the user understand?"

What organizations can do:

- Test consent with real users and ask them to explain, in their own words, what they think they agreed to.
- Include simple summaries, comprehension checks, or opportunities for users to ask questions, particularly for higher-risk applications.
- Develop indicators that measure user understanding and confidence, not just consent completion rates.

5. Design for the people using your tool

A consent process that works well in one setting may not work in another. Language, literacy, disability, culture, age, connectivity, and digital experience all influence how people understand and respond to consent requests.

What organizations can do:

- Co-design consent materials with the communities who will use the tool.
- Test different formats with diverse groups of users, particularly those who may face barriers to understanding.
- Adapt language, visuals, and delivery methods to reflect local contexts and user needs.

6. Redefine what success looks like

One of the most thought-provoking discussions during the session challenged how organizations measure success. Digital products are often judged by the number of users they attract, how long people stay engaged, or how many complete onboarding. Isabelle questioned whether those are the right metrics when informed consent is the goal. If clearer information helps users make more informed decisions, some may decide not to use a service or choose not to share certain data. That should not automatically be viewed as a failure.

What organizations can do:

- Review whether product success metrics prioritize user understanding alongside uptake and retention.
- Measure whether users understand how their data will be collected and used, not simply whether they clicked "Accept."
- Recognize that users choosing to opt out after receiving clearer information may reflect stronger agency and more meaningful consent, rather than poorer product performance.

7. Start improving now

AI technologies are evolving much faster than guidance, regulation, and organizational practice. Organizations do not need to wait for perfect standards before strengthening informed consent.

What organizations can do:

- Review existing digital tools and identify where consent could be clearer or more meaningful.
- Pilot small improvements, such as simplifying language, adding visual explanations, or creating opportunities for users to revisit consent.
- Treat informed consent as an ongoing learning process, regularly testing, adapting, and improving based on user feedback.

Resources for Further Learning

If you're interested in exploring this topic further or reviewing your organization's current approach to informed consent, the following resources provide practical guidance and examples.

Isabelle Amazon-Brown

Isabelle regularly shares practical insights on inclusive design, AI ethics, informed consent, and digital product design.

- Website: <https://isabelleamazon.com>
- LinkedIn: <https://www.linkedin.com/in/isabelle-amazon-brown-a3347351/>

Try the informed consent prototypes

During the session, participants tested three prototype approaches designed to improve informed consent for AI tools. They are available online and provide useful inspiration for organizations thinking about redesigning their own consent processes. If you have any questions or feedback about these prototypes, or would like support exploring how to improve your own informed consent processes, you can reach out to Isabelle [here](#).

- Quiz: <https://icprototypequiz.netlify.app/>
- Visual: <https://icprototypevisual.netlify.app/>
- Data: <https://icprototypedata.netlify.app/>

Other Resources

- <https://thelivinglib.org/ebola-a-big-data-disaster/> - Sean Martin McDonald: Ebola: A Big Data Disaster
- <https://www.scirp.org/reference/referencespapers?referenceid=3986524> - A. MdConald and LF Cranor: The Cost of Reading Privacy Policies

Final Reflection

This session marked the final webinar in the Equity & AI Learning Series. Thank you to everyone who participated throughout the series, and to the incredible speakers who generously shared their knowledge, experiences, and practical lessons. Together, we explored how AI can be designed and used in ways that are more ethical, equitable, and human-centred.

I hope the ideas and practical lessons shared in this resource spark new thinking and conversations within your own work. As AI continues to evolve, informed consent will remain a critical part of designing digital tools that build trust, support meaningful choice, and protect the rights and agency of the people they are intended to serve.

If you have questions, reflections, or examples from your own work, I would love to hear from you and continue the conversation.

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